



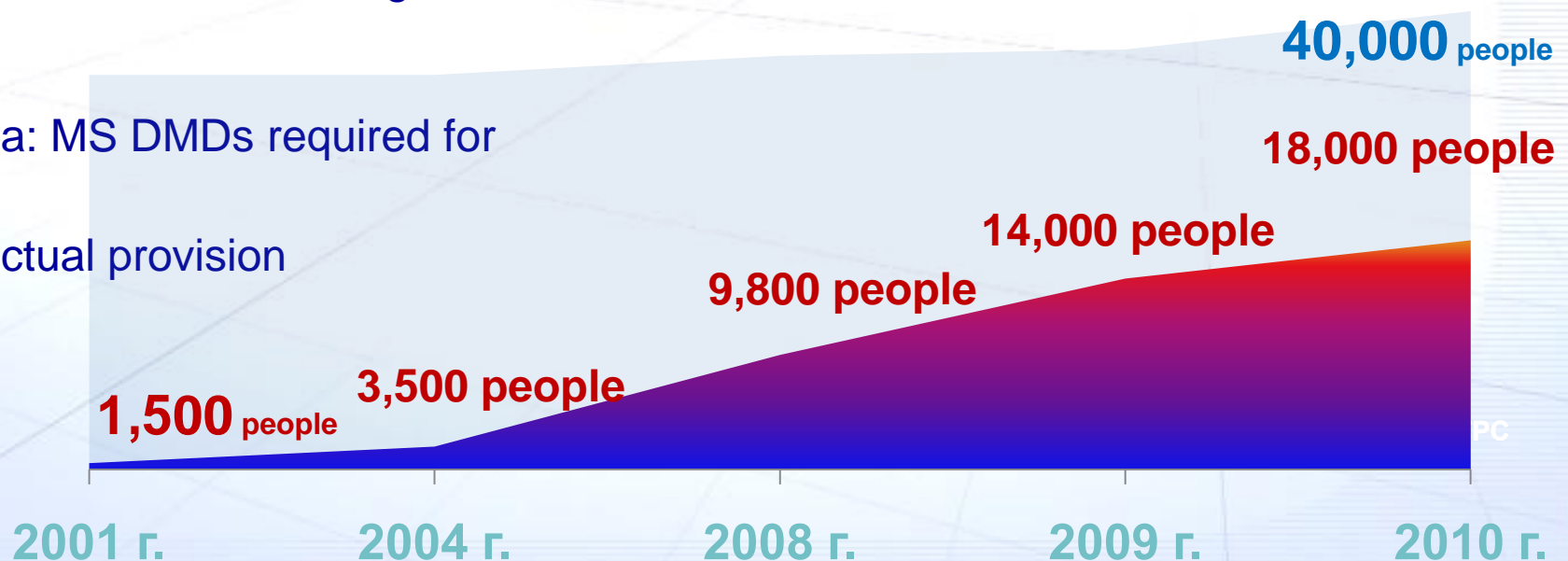
Plenipotentiary Public Experts at the All-Russian MS Society

**/ All-Russian Public Organization of
Disabled People with Multiple Sclerosis**

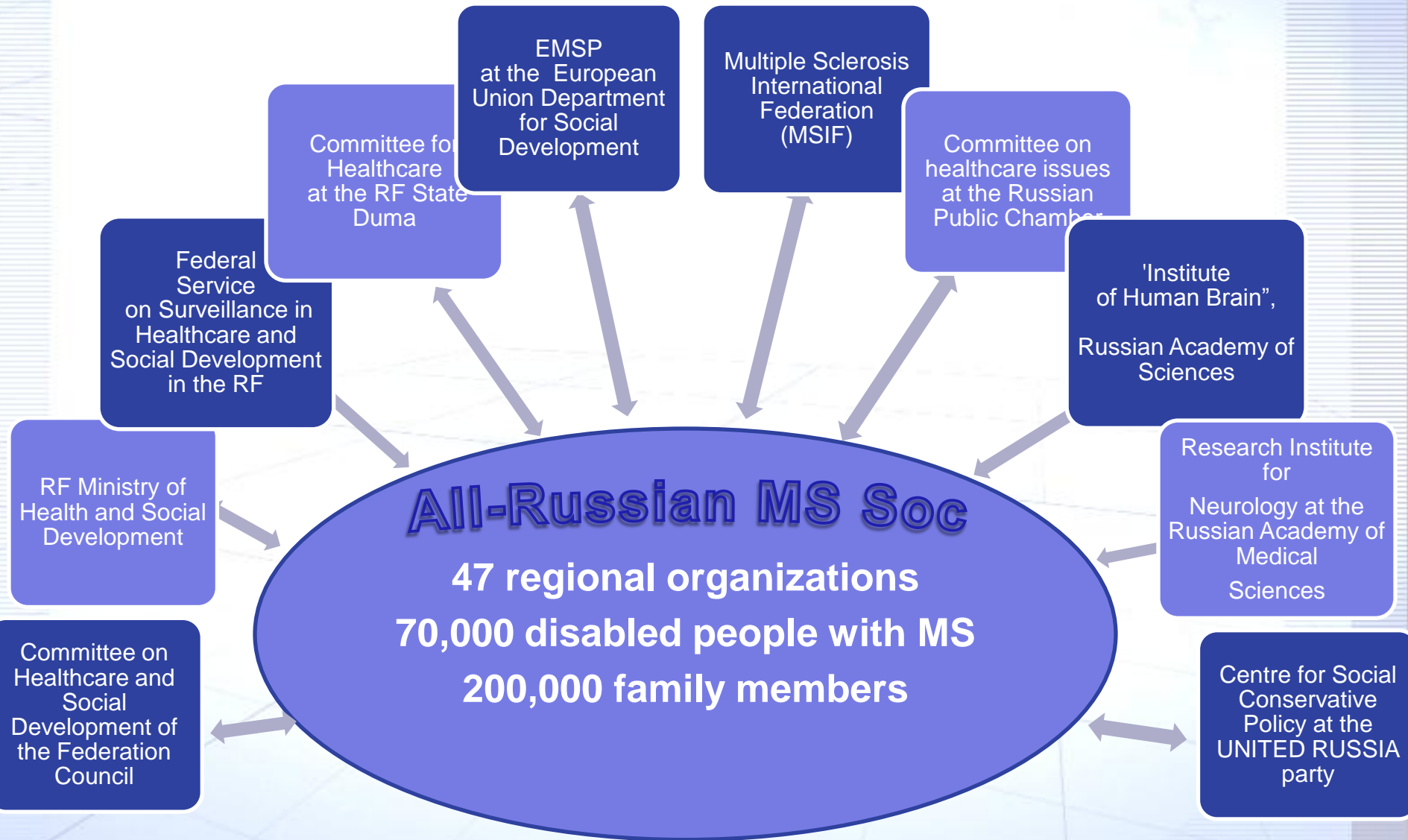
There are 130,000 PwMS in Russia

- 70%** families break up after one of the spouses is diagnosed
- 29%** patients have not left their homes for over a year
- 78%** patients are females under 50
- 75%** patients have disabilities
- 35%** are young people under 28
- 6%** are children aged 10-15

Russia: MS DMDs required for
and actual provision



Partners



Collaboration



Structures



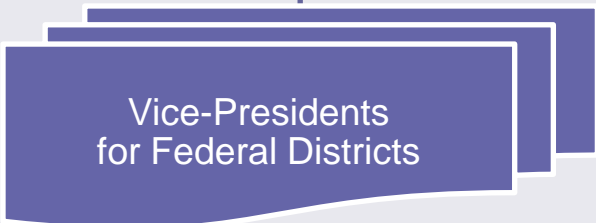
Russian Federation



ALL-RUSSIAN MS SOC.

PPE

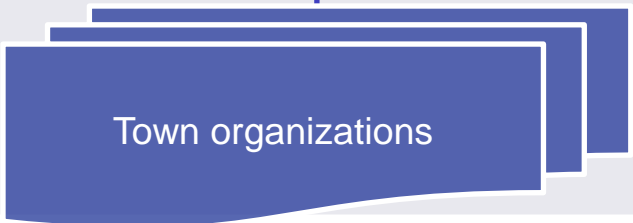
Federal District



Federation Constituents



Municipal Authority



PPE Mission

Advocacy and implementation of constitutional rights of Russian citizens for quality assistance and social rehabilitation

PPE goal

Organizing public inspection in execution of the Russian legislation in healthcare and social protection of people and helping patients, authorities and public to communicate

PPE objectives

1. to ensure the coordination of the activities of regional bodies of the executive authorities in the respective Constituent of the RF and non-for-profit organizations that deal with the issues of persons with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis;
2. to ensure control over implementing the provisions of the Fundamentals of Legislation of the Russian Federation about people's health protection passed on 22 July 1993 5487-1 (in particular, Article 62 in the Fundamentals), of the Federal Law "About Pharmaceuticals" passed on 22 June 1998 #86-FZ, on the issues of improving the pharmaceutical support for persons with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis within the territory of the Constituent of the RF;
3. to carry out analysis of the efficacy of the activities of regional bodies of the executive authorities in the respective Constituent of the RF and non-for-profit organizations that deal with the issues of persons with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis; to submit relevant initiatives to the Director General of the All-Russian Public Organization of Disabled People with Multiple Sclerosis;

PPE objectives

5. to participate in developing the programme for social and economic territorial development within the territory of the Constituent of the RF in cooperation with executive authority bodies and non-for-profit organizations that deal with the issues of persons with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis within the frames of the problem of people who have developed multiple sclerosis;
6. to organize control over execution of maintaining control and surveillance of activities on rendering the state social assistance to people in the form of providing social services in accordance with the Federal Law “About the state social assistance” passed on 17 July 1999 #178-FZ (edited in the Federal Law passed on 22 August 2004 #122-FZ), of other federal laws, statutory orders and instructions of the President of the Russian Federation, regulations and instructions of the Government of the Russian Federation, over implementation of the federal programmes in the Constituent of the RF regarding persons with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis;

PPE objectives

7. to take part in the work of Clinical Expert Committees (CECs) with regard to assigning high-priced drugs to people with multiple sclerosis on the basis of the demand to normalize and optimize the area of drugs circulation, as well as of the current demand for implementing the state control and surveillance of activities on rendering the state social assistance to people in the form of providing social services in accordance with the Federal Law “About the state social assistance” passed on 17 July 1999 #178-FZ (edited in the Federal Law passed on 22 August 2004 #122-FZ);
8. to submit to the Director General of the All-Russian Public Organization of Disabled People with Multiple Sclerosis, initiatives on the activities of bodies of the executive authorities in the Constituents of the Russian Federation, should these activities be inconsistent with federal laws, international liabilities of the Russian Federation or violate the rights and liberties of man and citizen with regard to people with the diseases attributed to the direction of activities of the All-Russian Public Organization of Disabled People with Multiple Sclerosis;

PPE objectives

10. to cooperate with the representative of the Federal Service on Surveillance in Healthcare and Social Development (Roszdravnadzor) in the Constituent of the RF when organizing inspections, in the Constituent of the RF, for carrying out federal laws, statutory orders and instructions of the President of the Russian Federation, regulations and instructions of the Government of the Russian Federation;
11. to cooperate with the representative of the Federal Service on Surveillance in Healthcare and Social Development in the Constituent of the RF with regard to perfecting the provision for healthcare establishments and persons with quality pharmaceuticals that fall into the specific directions, which interest the All-Russian Public Organization of Disabled People with Multiple Sclerosis and are not out of the frames of their powers in accordance with the Law of the Russian Federation.

PPE principles

- The key responsibility of a Plenipotentiary Public Expert shall be to care for the health and well-being of each patient with multiple sclerosis. The PPE shall be objective, put the health and well-being of a patient before personal or commercial interests, promote the right of a PwMS to secure and effective treatment and rehabilitation.
- The PPE shall be making efforts to be aware of PwMS's needs in the area of his/her responsibility.
- The PPE shall be informed about what legislative enactments provide for in the sphere of MS and enable development, legal literacy of people affected by MS as well as their capacity to advocate their own rights.
- The PPE shall organize, coordinate and control the activities to keep timely information incoming on the accuracy of regional and federal tenders developed to provide people with MS with pharmaceuticals. For this matter, the PPE shall encourage the continuity of communications between patients, authorities, medical care facilities, pharmacological companies and non-governmental organizations in issues of meeting the rights of a person with MS to secure and effective treatment and rehabilitation.
- The PPE shall be aware of any abuse of the federal law, the abuse scale and main challenges, which prevent carrying out the programme to let people get high-priced pharmaceuticals and enjoy provision of essential pharmaceuticals in meeting the right of people affected by MS to getting the timely and good quality medical and social assistance.

PPE principles

- The PPE shall respect the independence and dignity of a client to information about decisions having to do with providing him/her with pharmaceuticals. The PPE shall be plenipotentiary to consider requests and complaints of patients, PwMS, and, if necessary, to also negotiate with authorities the restoration of PwMS's violated rights.
- The PPE shall protect the right of a patient for confidentiality.
- When the PPE is involved in developing ways of delivery and provision of drugs for patients, he/she must be certain that it is done for the convenience of the patients.
- The PPE shall similarly treat all medicine-producing companies. The PPE shall keep in mind lest personal or commercial interests or social considerations interfere with his/her keeping neutral and that he/she fulfill patients' trust.
- The PPE shall keep up and constantly develop his/her expertise and skills.
- The PPE shall collaborate with colleagues and other experts and respect their system of values and professional abilities.
- The PPE shall be fair and reliable as far as his/her professional interrelations are concerned.
- The PPE shall be morally obliged in return to trust, the society has in him/her as an expert representative.
- The PPE shall contribute to the system of healthcare and social protection.

Preface

- 1992** Establishing the St.-Petersburg public organization 'North-West MS Association'
- 1996** Establishing the Samara regional public organization of disabled people with MS
- 1998** 7 regional public MS organizations activities are at work
- 1999** International MS Conference held in Samara

Proclamation

- 2001** Congress of representatives of 48 Russian regions proclaimed the All-Russian MS Society
- 2001** The All-Russian MS Society participated in the First All-Russian Civil Forum of NGOs
- 2001** Annual participation in working symposia held by the European MS Platform (EMSP) at the European Union Department for Social Development started
- 2002** Development and incorporation of the first Russian regional target programme to support disabled people with MS in the budget of the Samara oblast

Expansion into regions

- 2002** Establishing the Polyfunctional Neurocentre for disabled persons with MS in Samara
- 2002** Engaging regional branches in the work of the Public Committees at governors' offices and the health ministries, in the activities of the health committees at the legislative assemblies in 5 regions of the Russian Federation (RF)
- 2003** Development of the discussion and passing of target regional programmes to support disabled people with MS in 12 regions of Russia
- 2003** Conducting investigation of possibilities to adopt Regional Target Programmes to support disabled people with MS in 28 regions of the RF



Partnership with authorities

- 2003** Permanent cooperation of the All-Russian MS Society with the Healthcare Committee at the State Duma (Parliament) of the Russian Federation launched
- 2004** Conducting the All-Russian Working Conference at the Health Ministry of the RF that tackled issues of medical and social rehabilitation of disabled people with MS
- 2004** Participation in Parliamentary Hearings at the State Duma of the RF, in the forum of the Federation Council, in the meeting of the MS International Federation (MSIF), in Public Hearings on budget development in 13 regions of the RF
- 2005** Engaging in the work of the Committee on healthcare issues at the Public Chamber of the Russian Federation

Acknowledgment

- 2006** Attracting representatives of the State Duma, the Federation Council, the Public Chamber, the Public Council at the President Administration to the campaign to ensure allocation of funds for the “Programme of 7 nosologies”
- 2006** Signing the agreement on cooperation with the Federal Service on Surveillance in Healthcare and Social Development (RosZdravNadzor). Establishing the Institute of Plenipotentiary Public Experts (PPEs) and the Nursing Service.
- 2008** Entering the EMSP at the European Union Department for Social Development
- 2009** Entering the Multiple Sclerosis International Federation (MSIF)
- 2010** On All-Russian MS Society’s initiative, establishing the All-Russian Patients Union



experience 350 regional seminars and round-tables
490 publications in media
195 public hearings
44 Applied conferences
36 grant projects
23 press-conferences

ACHIEVEMENTS

180 million rubles (5 million euro) was allocated on target regional programmes developed on the initiative of the All-Russian MS Society throughout the RF in 2001-2005.

With the participation of the All-Russian MS Society, the RF Government and State Duma have allocated 99 billion rubles (2.8 billion euro) to treat patients with chronic disabling diseases for the period of 2008-2010.

In 2010, Plenipotentiary Public Experts (PPEs) delegated by the All-Russian MS Society take part in developing regional lists of people with MS and controlling the federal budget financing of the pharmaceutical provision in 75 regions. Nurses work in 55 regions of the RF.

